Primary Healthcare and Hospice Palliative Care

Fred Burge & Beverley Lawson

NSHPCA Annual Meeting, May 9, 2014
DISCLOSURE

- Fred Burge
- Relationship with Commercial Interests
  - I have no relationship with commercial interests.
DISCLOSURE OF COMMERCIAL SUPPORT

– I HAVE RECEIVED NO COMMERCIAL SUPPORT TO PARTICIPATE IN THIS SESSION.
– THERE IS NO POTENTIAL FOR CONFLICT OF INTEREST.
MITIGATION OF POTENTIAL BIAS

- I HAVE RECEIVED NO COMMERCIAL SUPPORT FOR THIS SESSION AND NONE OF THE COMMERCIAL SPONSORS OF THE OVERALL CONFERENCE WERE INVOLVED IN THE CONTENT DEVELOPMENT OF THIS SESSION.
Why did I tell you that story..

• Because I want us to keep in mind WHY we are trying to organize our health system better to make Mrs. G’s dying and the thousands like her, as good as it can be.

• What I want to say:
  – What is modern Primary Healthcare?
  – What are some key research findings in Nova Scotia?
  – How can PHC be a part of an integrated healthcare system that supports patients nearing death?
  – The Way Forward
What are the pressures ahead of us?

• Aging of the Canadian population
• Rapid growth in prevalence of chronic disease
• Doubling of number of people dying per year from chronic disease by 2056
• Lack of desire and capacity to have “dying in hospitals”
• Need to reduce costs of last 6 months of life.
So… just what do I mean when I say: Primary Healthcare?
Why strengthen primary care?

• Countries with a strong primary care orientation:
  – have demonstrably better health outcomes
  – better health equity,
  – lower mortality rates
  – lower overall costs of health care

• Access to a “health-care” home that provides first-contact care that is person-focused over time, comprehensive and coordinated is associated with better individual and population health, lower costs of care and reduced inequality.
Primary Healthcare in Canada: The slow (r)evolution….

• In 2000 the Canadian (federal) government, under the leadership of the first ministers agreed to provide funding to “kick-start” change in PHC

• Across Canada: The ‘Primary HealthCare Transition Fund’ (PCHTF)
The five common objectives of the PHCTF

- to increase the proportion of the population with access to primary health care organizations which are accountable for the planned provision of comprehensive services to a defined population;
- to increase the emphasis on health promotion, disease and injury prevention, and chronic disease management;
- to expand 24/7 access;
- to establish multi-disciplinary teams;
- to facilitate coordination with other health services
- To implement EMR technology
New models of PHC

• Different provinces have built solutions responding to the objectives in a variety of ways
  • Ontario: Family Health Groups, Teams, Network
  • Quebec: Groupes des Medicines Familiale
  • Alberta: Primary Care Networks

• Nova Scotia has seen growth in interdisciplinary teams, EMR penetration and population based planning.
Primary Care Doctors’ Use of Electronic Medical Records in Their Practice, 2009 and 2012

Percent

NETH | NOR | NZ | UK | AUS | GER | US | FR | CAN | SWIZ
--- | --- | --- | --- | --- | --- | --- | --- | --- | ---
99.98 | 97.98 | 97.97 | 96.97 | 95.92 | 82 | 69 | 68 | 67 | 56 | 41

<table>
<thead>
<tr>
<th>Has:</th>
<th>Aust (%)</th>
<th>NZ (%)</th>
<th>Canada (%)</th>
</tr>
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<tbody>
<tr>
<td>Practice nurse</td>
<td>83</td>
<td>98</td>
<td>54</td>
</tr>
<tr>
<td>Practice manager</td>
<td>74</td>
<td>74</td>
<td>58</td>
</tr>
<tr>
<td>Open after 6pm (at least once a week)</td>
<td>50</td>
<td>40</td>
<td>55</td>
</tr>
<tr>
<td>Open weekends (at least once a month)</td>
<td>75</td>
<td>43</td>
<td>39</td>
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</table>

Access within practice/centre to:

<table>
<thead>
<tr>
<th></th>
<th>Aust (%)</th>
<th>NZ (%)</th>
<th>Canada (%)</th>
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<tbody>
<tr>
<td>Lab facilities</td>
<td>42</td>
<td>25</td>
<td>30</td>
</tr>
<tr>
<td>X-ray facilities</td>
<td>6</td>
<td>14</td>
<td>19</td>
</tr>
</tbody>
</table>
# Practice Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Aust (%)</th>
<th>NZ (%)</th>
<th>Canada (%)</th>
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<tbody>
<tr>
<td><strong>Receive feedback:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescriptions or referrals</td>
<td>60</td>
<td>93</td>
<td>12</td>
</tr>
<tr>
<td>Peer review by colleagues</td>
<td>31</td>
<td>72</td>
<td>18</td>
</tr>
<tr>
<td>Patient satisfaction</td>
<td>47</td>
<td>51</td>
<td>25</td>
</tr>
<tr>
<td><strong>Use medical records for lists by:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>41</td>
<td>64</td>
<td>26</td>
</tr>
<tr>
<td>Diagnosis/risk factor</td>
<td>69</td>
<td>92</td>
<td>44</td>
</tr>
<tr>
<td>Medications</td>
<td>40</td>
<td>63</td>
<td>20</td>
</tr>
<tr>
<td>Reminders</td>
<td>73</td>
<td>87</td>
<td>31</td>
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</tbody>
</table>
Service Integration

<table>
<thead>
<tr>
<th></th>
<th>Aust (%)</th>
<th>NZ (%)</th>
<th>Canada (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Almost) always received feedback from specialists</td>
<td>62</td>
<td>79</td>
<td>58</td>
</tr>
<tr>
<td>Receive hosp. discharge summary within 4 days</td>
<td>35</td>
<td>64</td>
<td>16</td>
</tr>
<tr>
<td>Meet &gt; 1 per month</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other GPs</td>
<td>82</td>
<td>87</td>
<td>84</td>
</tr>
<tr>
<td>Hospital specialists</td>
<td>17</td>
<td>9</td>
<td>32</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>33</td>
<td>51</td>
<td>54</td>
</tr>
<tr>
<td>Home care nurse</td>
<td>12</td>
<td>21</td>
<td>17</td>
</tr>
<tr>
<td>Midwife</td>
<td>7</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>Social workers</td>
<td>4</td>
<td>8</td>
<td>31</td>
</tr>
</tbody>
</table>
PHC in Nova Scotia

We’re moving forward slowly…. But forward..
Primary healthcare hospice palliative care research in Nova Scotia: What have we learned?

- Almost 20 years of research focused on services provided to adults at the end of life:
  - Most take a population perspective with a retrospective approach

- Secondary data analysis
  - Linkage of large administrative health database
  - Began with 2 in 1995; up to 10 linked in 2005
  - Cancer focused since able to identify through registry data

- Survey approach
  - All chronic disease causes of death
  - Bereaved family member perceptions of care (2009-13).
Networked Information System (NELS NIS)

Linked Dataset for Cancer and other Chronic Conditions with an End of Life Care Phase

- Cancer Registry (includes deaths from Vital Statistics)
- Death certificate information from Vital Statistics for all chronic conditions
- Chronic disease registries: Cardiovascular and Diabetes
- Mortality Follow Back Survey Responses
- Palliative radiotherapy and medical oncology
- Halifax and Cape Breton Palliative Care Program Data
- Hospital discharge data from Canadian Discharge Abstract database
- Family and specialist physician billings data
- Continuing care (home care and nursing home)
- Pharmacare and Prescription Monitoring Program databases
- Colchester Palliative Care Program data

3x3 NELS - see slides to follow

Medications in progress
Location of death & location of care

• Nova Scotians wish to die at home
  – 76% (1998-2000: the Rural Palliative Care Home Care project)
  – 74% (2009-11: Mortality follow-back study)

• Far fewer were able to
  – Out-of-hospital deaths among cancer patients
    • 1992-1997: 26% (death certificate)
    • 1998 to 2003: 32% (hospital discharge records)
    • 2004 to 2009: 41% (hospital discharge records)
    • 2009 to 2011: 51% (survey data, all chronic disease)
      – 39% of those who voiced a home preference did so
      – 84% voicing a preference for LTC did so
Family physician (FP) care for adults dying of cancer

Physician visits during the EOL*

• 1992 to 1998
  – FPs accounted for 63% of all visits (mean 19.4; SD 20.3)
  – 94% received at least one FP visit

• 1998 to 2003
  – FPs accounted for 59% of all visits (mean 22.9; SD 21.4)

• Across all years FPs account for the majority of home visits.

* last six months or less (~ cancer diagnosis date), unless stated otherwise
Provider continuity of care (COC) and outcomes

• In primary care, COC may be defined as:
  “… an uninterrupted succession of care by an individual provider, not limited by the patient’s illness, and facilitated by prior knowledge of the patient …”
  – it is experienced by an individual
  – it is experienced over time

• Can be measured by the frequency of encounters with varying providers or as an index of encounter concentration to a primary provider.
Provider continuity

- Modified modified continuity index (MMCI)
- A measure of concentration, scores range from 0 to 1
- Categorized as: ‘low’ (<0.5), moderate (0.5-<0.8) & ‘high’ (≥0.8).

Proportion of decedents by provider continuity continuity of care

<table>
<thead>
<tr>
<th>Provider continuity of care</th>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
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<tbody>
<tr>
<td></td>
<td>60%</td>
<td>45%</td>
<td>15%</td>
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</table>

family.medicine.dal.ca
Inspiring Minds. Impacting Communities.
Results: Provider continuity of care (COC) & ED visits

- Cancer patients receiving low provider COC made 3.9 times more ED visits during the end-of-life than those experiencing high provider COC (adjOR 3.9; 95%CI 3.6-4.3)

- And … those experiencing moderate COC made over twice as many ED visits than patients receiving high. (adjOR: 2.3; 95%CI:2.2- 2.4).
Results: Provider continuity (COC) and length of hospital stay

- Cancer patients receiving low provider COC spent 20% more days in hospital during the end-of-life than those experiencing high provider COC (adjOR: 1.2; 95%CI: 1.1-1.3)

- And those experiencing moderate COC spent 9% more days in hospital than patients receiving high. (adjOR: 1.1; 95%CI: 1.0-1.2)
Results: Provider continuity and location of death

- Cancer patients receiving high provider COC were 54% more likely to die out-of-hospital than those experiencing low COC (adjOR: 1.5; 95%CI: 1.2-1.9).
- Patients experiencing moderate continuity were 30% more likely than those receiving low (adjOR: 1.3; 95%CI: 1.1-1.7).
- But effect only among females
  - high vs low (adjOR 1.6; 95%CI: 1.1-1.3)
  - moderate vs low (adjOR 1.94; 95%CI: 1.36-2.75)
Family physician home visits

• 1998 to 2003
  – 45% received at least one home visit during last six months of life

• 2004 to 2009
  – 24% received at least one home visit during last 14 days of life
  – Large regional variation by DHA

• 2009 to 2011 (survey data)
  – Of those at home, 26% received a FP home visit during last 30 days of life
FP Home Visits
Regional variations across Nova Scotia

National benchmark
A
B
C
D
E
F
G
H
I

% Cancer patients

0 10.0 20.0 30.0 40.0
Research supporting benefits of FP home visits

FP home visits are significant INDEPENDENT contributors in:

- Achieving a desired home death
  - Patients receiving FP home visits were twice as likely to achieve a preferred home death (adjOR: 2.2; 95% CI: 1.1-4.5)

- Reducing emergency department (ED) visits
  - Cancer patients receiving FP home visits were 70% less likely to visit the ED during their last 14 days of life (adjOR: 1.7; 95% CI: 1.5-2.0)

- Having a signed advanced directive/living will
  - Patients receiving FP home visits were 90% more likely to have a signed advanced directive or living will (adjOR: 1.9; 95% CI: 1.2-2.9).
Homecare

• Limited electronic information became available in 2003
  – 71% of adults dying of cancer in 2003 had a homecare record
    • But, only 31% had an assessment recorded
    – 37% flagged as having a palliative intent

• 2005 to 2009 (4 province study)
  – 54% of all cancer patients were seen by homecare (assessed)
  – 54% received a nursing visit (RN or LPN)
  – 29% received personal home support
  – Of those seen by homecare, 85% flagged as palliative intent
Palliative Homecare
Regional variations across Nova Scotia

<table>
<thead>
<tr>
<th>Region</th>
<th>% Cancer patients</th>
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<tbody>
<tr>
<td>National benchmark</td>
<td>57.0</td>
</tr>
<tr>
<td>A</td>
<td>54.5</td>
</tr>
<tr>
<td>B</td>
<td>52.5</td>
</tr>
<tr>
<td>C</td>
<td>50.0</td>
</tr>
<tr>
<td>D</td>
<td>47.5</td>
</tr>
<tr>
<td>E</td>
<td>45.0</td>
</tr>
<tr>
<td>F</td>
<td>42.5</td>
</tr>
<tr>
<td>G</td>
<td>40.0</td>
</tr>
<tr>
<td>H</td>
<td>37.5</td>
</tr>
<tr>
<td>I</td>
<td>35.0</td>
</tr>
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% Cancer patients
Nova Scotia Homecare Palliative Intent

% flagged as palliative

Weeks prior to death
Nursing visits

Homecare nursing visits (2005 to 2009)

• Three province study to examine the dose-response association between increased homecare nursing hours/week delivered and hospitalization

• Secondary data analysis of provincial administrative health information

• 54% (n=5,557) of cancer patients received nursing visits through the provincial homecare program
  – 52% AFTER date of cancer diagnosis.
NS Nursing visit and hospitalization rates: last 26 weeks of life – not sure if hospital adds anything

Nursing visit rate

Hospital admission rate

Weeks prior to death

Weeks prior to death
Is hospitalization associated with nursing activity?

- In NS in last 4 weeks of life:
  - If >= 5hr nursing Hospitalization rate decreased by 16%
  - If Homecare was flagged as palliative hospitalization rate decreased by ~ 29%
Nursing visits

• Survey data tapping all chronic disease causes
• Of those at home any part of their last 30 days:
  – 63% were visited at home by a nurse
  – Nurses were identified as a major provider in help with symptom control and as a source of information

• Nursing visits also contribute independently to achievement of a desired home death
  – Patients receiving nursing visits at home were six times more likely to achieve a preferred home death than patients who did not (adjOR:6.2; 95%CI:2.6-14.4).
How can we “leverage” the innovation in PHC to result in better End of Life Care?

• Population based approaches
• Interdisciplinary teams
• Electronic Medical Records
  – Communication
  – Identification (registry)
  – Decision-support tools
• Alternate payment strategies
  – Including quality incentives
• Integration with other health system components
Identification in advance…

• How do we identify those at risk of dying in community primary care service delivery settings?
  – Office, home, and LTC?

• In Primary Care practice we might consider:
  – The ‘surprise’ question.
  – Using EMR to identify patients ‘at risk’
  – Using repeat service utilization data (ER, Hosp)
Manually think about them…
Use Electronic tools...

- EMR identification:
  - Run reports on those at risk
  - Use embedded algorithms created by others
    - MarNet-CPCSSN
      - 60 practices…. 90,000 patients
Once identified... then assess?

- Assessment tools for Primary Healthcare
  - Emerging in family practice
  - Exist in Homecare

PSP End of Life Care Algorithm

Manage Symptoms
- GPAC Part II: Pain and Symptoms
- Fracture Healing Symptoms Guidelines
  - Attention to symptoms distress can be early in the illness trajectory & should not be linked with prognostic EEG

Plan and Collaborate
- Transition 1: Disease advancement
  - Recognition and registry
  - Advance Care Planning
  - Identify client’s values and beliefs
  - Clarify illness trajectory, possible complications, prognosis, expected outcomes to inform goal
  - Consider need for referral/coordination w/MC

- Transition 2: Decompensation, experiencing life-limiting illness
  - Disease care coordination
  - Consider hospice palliative care referrals

- Transition 3: Dependency & symptoms increase
  - End of life Care Planning, including access to palliative care resources

- Transition 4: Decline & lost days
  - Discuss needs required in home, including access to palliative care resources

- Transition 5: Death & Bereavement
  - Have follow-up bereavement visits

Death Certificate
- Bereavement

End of Life Care Plan templates
- My Voice – including initial conversation
- End of Life Care Plan log template

BC Palliative Care Benefits form
- Palliative Care Services form
- Palliative Care Drug Formulary
- Palliative Care Form

Information in this document is based on the following references:

Dalhousie University
Faculty of Medicine
Department of Family Medicine

family.medicine.dal.ca
Inspiring Minds. Impacting Communities.
Canadian Models featuring a high degree of primary care physician involvement:

• British Columbia’s Practice Support Program
  – Fraser Valley, Vancouver Coastal Health Authorities
  – Integrates aspects of the UK’s Gold Standards Framework
  – Assessment, planning, co-ordination based in PHC

• Enhanced Palliative Care Team Shared Care Model (EPCT)
  – Niagara region of Ontario
  – Goal to enhance family physician (FP) capacity
  – Integrates primary and secondary systems by including the FP into a palliative care team
• Edmonton Regional Palliative Care Program
  – FPs and homecare staff are the primary palliative care providers / 24 hr on-call coverage
  – Supported by palliative care consulting services

• Palliative Care Integration Project (PCIP)
  – Southeast Ontario (5 sites)
  – Majority of palliative care provided via a network model of physicians, allied health professionals, site champions
• Integrated Client Care Project for Palliative Care
  – Ontario ‘Spotlight sites’ - launched September 2011
  – Integrated ‘systems wide’ approach led by local Health Integration networks (regions) and Community Care Assess Centres
  – Recognizes two groups of patients:
    • Complex needs (shared care)
    • Stable palliative needs (coordination).
Where to from here…

- We now have >100 PHC teams in NS
- We have an established Chronic Care Model for the province
- We have a strengthened interest from Palliative/Hospice care to work with PHC in moving a palliative approach earlier into the trajectory of Chronic disease in the notion of the new strategic “Way Forward” nationally and this week’s released provincial strategy
Where to from here…

• Strengthen PHC and thus strengthen the palliative approach
  – Teams
  – EMR utilization for identification and assessment
  – Planning care as a team
  – Finding ways to provide a ‘basket of services’
  – Practice Support programs

• Improve communication and coordination with others in community and with specialized HPC.
More research opportunities..

- CIHR Strategy for Patient Oriented Research
  - CBPHC Innovation Teams
  - Maritime SUPPORT centre
  - NS Primary and Integrated Healthcare Innovations Network
What I hope we’ll contribute collectively is…

Not just being story catchers like Brene Brown,

But rather, I hope we will all get our hands dirty by working together to improve how we help the most vulnerable die… and be not just story catchers but story shapers of the last chapter of people’s lives.
Thank you....
"It is not the critic who counts; not the man who points out how the strong man stumbles, or where the doer of deeds could have done them better. The credit belongs to the man who is actually in the arena, whose face is marred by dust and sweat and blood; who strives valiantly; who errs, who comes short again and again, because there is no effort without error and shortcoming; but who does actually strive to do the deeds; who knows great enthusiasms, the great devotions; who spends himself in a worthy cause; who at the best knows in the end the triumph of high achievement, and who at the worst, if he fails, at least fails while daring greatly, so that his place shall never be with those cold and timid souls who neither know victory nor defeat."
NOVA SCOTIA’S Adapted & Adopted CDM Model

COMMUNITY

- Build Healthy Public Policy
- Create Supportive Environment
- Strengthen Community Action

HEALTH SYSTEM

- Self Management/ Develop Personal Skills
- Delivery System Design/ Re-orient Health Services
- Information Systems
- Decision Support

Activated Community
Informed Activated Patient/Family

Productive Interactions & Relationships

Prepared Proactive Community Partners
Prepared Proactive Practice Team

Functional & Clinical Outcomes
Population Health
Determinants of Health
Community-based Primary Healthcare

Community-based primary health care (CBPHC) covers the broad range of primary prevention (including public health) and primary care services within the community, including health promotion and disease prevention; the diagnosis, treatment, and management of chronic and episodic illness; rehabilitation support; and end of life care.

CBPHC involves the coordination and provision of integrated care provided by a range of health providers, including nurses, social workers, pharmacists, dietitians, public health practitioners, physicians and others in a range of community settings including people's homes, healthcare clinics, physicians' offices, public health units, hospices, and workplaces.

It is delivered in a way that is person- and population-centred and responsive to economic, social, language, cultural and gender differences.
Community Based PHC (CIHR)

- cover[ing] the “broad range of primary prevention (including public health) and primary care services within the community, including health promotion and disease prevention; the diagnosis, treatment and management of chronic and episodic illness; rehabilitation support; and end-of-life care”
- Patient and population centered
- Multiple providers
- Multiple settings.
Opportunity....

Primary Healthcare Continuum

The Palliative Approach
Core Elements: Identify, Assess, Plan & Collaborate, Delivery

Early
Diagnosis of chronic conditions

Disease containment
Maintaining function

Decompensation
Experiencing life limiting conditions

Decline
Dependency & symptoms increase

Death
Bereavement

TRANSITIONS

Birth

Time

family.medicine.dal.ca

Faculty of Medicine
Department of Family Medicine

Dalhousie University
Inspiring Minds. Impacting Communities.
NS Nursing visit rate – last 26 weeks of life

Weeks prior to death

Nursing rate
In an early data linkage study we examined if greater continuity of primary medical care for cancer patients during the end-of-life was associated with:

- Emergency department (ED) utilization
- Total length of hospital stay (LOS)
- Location of death

Subjects: All adults who died of cancer in Nova Scotia as identified from the death certificate between 1992 & 1997 AND having at least 3 ambulatory visits to a FP during the last 6 months of life (n=9795).